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Health-related quality of life and its association with self-esteem and fatigue among children diagnosed with cancer

ABSTRACT

Aims and objectives: The aims of this study were to identify the links between self-esteem, fatigue and health-related quality of life for children and young people during and following treatment for cancer.

Background: Measures to minimize adverse outcomes for survivors of childhood cancer have been developed, but the crucial periods of returning to school and transition to adult life and adult services are not addressed so well. Screening of quality of life, fatigue, and self-esteem in childhood cancer patients during and after treatment is important for optimizing the nursing response and improving outcomes for children.

Design: A cross-sectional, descriptive, correlational, comparative survey was designed.

Methods: Validated measures of the attributes being studied were used. This study was conducted in private rooms on the ward and in the out-patient clinic of a major oncology hospital in Jordan in 2015. Seventy children aged 5-16 years were included. Ethical approval was secured.

Results: The age range of the children was 5-16 years (mean 10.17, SD 3.4 years). Thirty were girls and 40 were boys. The total quality of life scores ranged from 21 to 100 ($m=65.5$; $SD=17.6$). The total scores of fatigue range from 12.5 to 100 ($m=65.79$; $SD=22.20$). Children with a high level of fatigue experienced lower quality of life.

Conclusion: Continuing education centers at hospitals may find the results of this study helpful to provide professional updates and training events to enhance nurses' understanding of psychosocial distress responses and ability to intervene effectively within the multi-professional effort.

Relevance to clinical practice: The outcomes of this study may enhance the development of guidelines for routine assessment by nurses and others of these factors among children with cancer. The nursing role in ensuring holistic care and attention to the problems of most concern to patients could be strengthened.

Key words: Childhood cancer, Jordan, quality of life, self-esteem, nursing practice.

What does this paper contribute to the wider global clinical community?

- Childhood cancer exerts significant impacts on children's quality of life, fatigue and self-esteem. The nature of the links between these factors has been clarified.
- Professional education and training programmes for nurses and other staff members addressing support in all of these areas for children with cancer are of vital importance.
- Understanding the complex links between these aspects of survivorship should help to optimise nursing responses to patient-prioritised problems and to engage in pre-emptive supportive therapy.

INTRODUCTION

In 2010 in Jordan, 231 children aged 1-14 years were diagnosed with a new cancer. Overall survival following diagnosis of a cancer in childhood is now approximately 70% (Ministry of Health 2010). Survivors of childhood cancer are challenged by varied problems, physical, psychological and social in nature. These vary with the nature of the cancer and associated treatment, and can be of equally variable intensity and longevity. For example, the rate of diagnosis of a tumour in the central nervous system in children is approximately 350 per year in the UK (Feltbower et al. 2014), and though approximately 70% are expected to reach survivorship, many do so with significant physical, sensory and cognitive impairments. Such children are likely to be troubled by problems with neurological functioning, epilepsy, vision, hearing, short stature, endocrinopathy and social functioning (Anderson et al. 2001, Panesar et al. 2008). Many children with cancer experience serious impairment in health-related quality of life (HRQL) that becomes apparent from the point of diagnosis, intensifies through treatment and may then persist into survivorship. This study was undertaken to clarify the links between self-esteem, fatigue and HRQL in children and young people with cancer in Jordan, and to establish which factors are reported by children to have the greatest impact on these attributes. No previous studies were found to have investigated this issue in Jordan or the Middle East. This study will add further to the breadth of understanding of the problem in the international literature from the Jordanian perspective.

BACKGROUND

Although measures to minimise adverse outcomes for survivors of childhood cancer have been developed, the crucial periods of returning to school and transition to adult life and services tend to fall outside such efforts (Brier et al 2015). This is linked to a factor that is often emphasised by adolescent patients: loss of social networks and peer relations. In a study of adolescents with myelomeningocele, Müller-Godeffroy et al (2008) found an emphasis in reports of the importance of peer relations, together with a corresponding reduction in reported HRQL in the fields of emotional well-being, self-esteem, and peer relations. Furthermore, Pini et al (2013) found in the UK that when peer relations were kept intact, reintegration into school was likely to be more successful, and a more positive experience of school was reported.

A significant correlation was found by French et al (2013) between poor physical quality of health and absence from school in Canadian children. For survivors of brain tumours, cognitive impairment often detracts from achievement at school, this combined with absenteeism further militating against a positive school experience. This neurocognitive impairment may well continue to exert effects into adulthood (Ellenberg et al 2009). A central role is identified by Moore et al (2013) for paediatric oncology nurses to identify those children at risk of such outcomes in order to instigate early intervention to counter expected limitations. Children with standard risk acute lymphoblastic leukaemia (SR-ALL) may be expected to suffer physical and social impairments during and for some months after treatment, recording significant reduction in HRQL (Mitchell et al 2016). They and their families require long-term support.

In a Swedish study by Sundberg et al (2009), a raft of physical impairments and limitations to participation in physical activities were the most commonly reported negative outcomes for

young adult patients. However, other studies have found that suboptimal health behaviours are often adopted by survivors of childhood tumours (Brier et al 2015; Demark-Wahnefried et al 2005), and population-appropriate means of delivering health messages are essential to promoting long-term health. Indeed, for many cancer diagnostic groups in childhood, understanding the impact of the disease and the treatment on children's responses is crucial to intervention to improve long-term outcomes for children and families (Fan & Eiser 2009, Msall 2010, Li et al 2013). In a metasynthesis of Chinese and English evidence, Lee et al (2012) noted that, given appropriate support, survivors of childhood cancer could regain a positive outlook and self-image.

The personal response of children to treatment for cancer is important for their wellbeing during treatment and can impact on outcomes such as HRQL, health status and psychological wellbeing afterwards. Self-concept, an alternative term for self-esteem, refers to people's perceptions and feelings about themselves, including feelings of self-confidence, self-worth, self-acceptance and ability (Marsh et al 1983). A Greek study found that the role of self-esteem in moderating these attributes is not clear, but self-esteem might be damaged significantly by the effects of cancer and its treatment (Kyritsi et al 2009). However, some of these studies have been criticised for failing to distinguish between children with different diagnoses, or those at differing treatment stages (Cantrell 2007, Eiser et al 2000, Landolt et al 2006, Wakefield et al 2010). Psychological wellbeing is an additional challenge after a diagnosis of cancer in childhood. Myers et al (2014) recognised anxiety to be a common problem in some patients with SR-ALL, and this resolves into depression for at least a year afterwards. Canning et al (2014) found the most significant predictors of emotional distress for child cancer patients to be self-concept and cancer-specific HRQL. Von Essen et al (2000) found that self-esteem could be maintained by Swedish children with cancer while under treatment, but that during follow-up this could deteriorate to pathological levels.

Fatigue during and after cancer treatment is a major problem for children and adolescents (Gibson et al 2005) and is multifactorial in nature, exerting an impact on functional status (Edwards et al 2003). Fatigue is problematic throughout the stages of cancer treatment and recovery (Tomlinson et al 2013). For children, particularly, the aggressive treatment that is often required to secure a cure can provoke profound fatigue (Yeh et al 2008). A clear link has been found between cancer-related fatigue and HRQL (Eddy & Cruz 2007).

Caregivers are also adversely affected by children's cancer experiences. Carers often neglect their own health and physical needs, accepting significant reduction in their own quality of life as part of their caregiving function (Al-Gamal 2013). In an Italian study, parents of children with a brain tumour often experienced profound anxiety and depression (Finocchiaro et al 2012). Although there was a correlation between the severity of treatment and late effects endured by young adults and the distress experienced by them and their parents, reduction in parental distress was also reflected in a reduction in the patient's distress (Robinson et al 2009). The complexity of such interactions requires careful assessment in clinical practice and in research.

Research from The Netherlands shows screening of HRQL, psychological or emotional wellbeing, and self-esteem in childhood cancer patients and their caregivers during and after treatment to be important for optimising the professional response and improving outcomes for

children and families (de Ruiter et al 2016). Gerhardt et al (2007) found American brain tumour survivors to be capable of completing psychological measures without this prompting distress. However, careful selection of instruments, and thoughtful application of patient-reported and proxy (parent) reported outcomes are necessary. Self-reported HRQL by children and adolescents with myelomeningocele were found to be effective in establishing the impact of clinical impairment in a German study (Müller-Godeffroy et al 2008). However, a systematic review by Savage et al (2009) in Ireland found little consistency in application of instruments to measure HRQL in children with acute lymphoblastic leukaemia, and significant variation between patient-reported and parent-reported quality of life for the child. In contrast, Canning et al (2014) found reports of the patient's self-concept and HRQL by children and their parents to be highly consistent. They concluded that parental reports of a child's HRQL can be valid and reliable. Al-Gamal and Long (2010) also found parents of Jordanian children with cancer able to complete extensive instruments without burden or emotional distress.

METHOD

Aims

The aims of this study were to identify the links between self-esteem, fatigue and HRQL for children and young people during and following treatment for cancer, and, second, to establish which factors are reported by patients to impact on these attributes.

Research Questions

1. What are the experienced health-related quality of life, self-esteem and fatigue among children diagnosed with cancer in Jordan?
2. Is there a relationship between children's health-related quality of life and their self-esteem?
3. Is there a relationship between children's health-related quality of life and the fatigue that they experience?
4. Is there a relationship between demographic variables and children's health-related quality of life?

Design

A cross-sectional, descriptive, correlational, comparative survey was designed, employing validated measures of the attributes being studied. This study was conducted in private rooms on the ward and in the out-patient clinic of a major oncology hospital in Jordan. Recruitment was delayed until after recovery from any surgery.

Sample

Seventy children aged 5-16 years who were diagnosed with cancer and visited the hospital between January 2015 and June 2015 participated. During this period, every child who met the selection criteria was considered for inclusion. Only three families declined, indicating minimal impact of selection bias. There are no peak periods of admission for cancer so the period selected for recruitment was not an issue. The inclusion criteria were that patients had to be aged 5-16 years and diagnosed with cancer (of any type) and they had to be able to speak Arabic (the first language of Jordan). Children with terminal cancer were excluded in order to

prevent causing unwarranted psychological burden for the family. Most patients were still on treatment, though a minority was in follow-up. The minimum time of recruitment after diagnosis was seven months, and the maximum time was four years.

Data collection

The nurse coordinator helped in identifying eligible children who had an appointment in the clinic, explained the study, and, if agreeable to participate, introduced the family to the research team. One researcher helped the child to complete the instruments. For younger children (5-12 years) the research assistants read the instrument questions and the possible responses to the child and made sure that the child understood the items and the rating scale. Children aged 13-16 years completed the instruments independently in the presence of a researcher. It was accepted that if a child were unable to respond to an age-appropriate module, the lower age module would be used. Parental proxy versions of the instruments were not required. Each data collection episode lasted for approximately 30-45 minutes.

Instruments - Demographics

For the purpose of this study the researchers developed a demographic questionnaire to collect information regarding the patients' age at diagnosis, sex, cancer type, socioeconomic background, and baseline neurological functioning after surgery and treatment.

The PedsQL 4.0 Generic Core Scale

In order to measure health-related quality of life, the PedsQL 4.0 Generic Core Scale was used. This paediatric quality of life core scale covers four domains of Physical, Emotional, Social and School functioning (Varni et al 2002). A number of age-range and patient/parent-reported versions are available. Each item is scored from 0 to 4 so that the best total HRQL is scored at 0 and the worst at 92. The scoring instructions indicate that items should be reversed-scored and then a linear transformation made to a 0-100 scale in which a higher score is indicative of better HRQOL. The originator states that no cut-off scores to establish a threshold between high and low scores are supported by the PedsQL instruments. The validity and reliability of the Arabic version has been reported in a Jordanian study, and Cronbach alpha was 0.90 (Arabiat et al 2011). The main researcher gained permission to use the Arabic (Jordan) validated version of this instrument from Mapi Trust. In this study Cronbach alpha was 0.88.

The PedsQL Multidimensional Fatigue Scale

This 18-item scale measures fatigue in children and covers generic, sleep and cognitive-related topics in relation to fatigue (Varni et al 2004a). The reliability of the scale was 0.89. The same scoring system is applied as above, but with 18 items in the scale, the minimum total score is 0 and the maximum is 72. A non-verified Arabic version was acquired, minor modifications were made, and then the process of back translation was completed. Two experts checked the revised instrument for face validity. In this study Cronbach alpha was 0.90

The Self-Description Questionnaire (SDQI and SDQII)

Self-esteem among children was measured using the Self-Description Questionnaire (Marsh et al 1983). This is a multi-dimensional self-concept instrument with strong psychometric properties. There are three versions: SDQI for pre-adolescence or primary school, SDQII for young adolescence (12-16 years) or secondary school, and SDQIII for late adolescence. The

SDQ measures four attributes in non-academic areas (Physical Ability, Physical Appearance, Peer Relations, and Parents Relations), and three academic-related fields (Reading, Mathematics, and School in general). SDQII introduces an additional two subscales of Emotional stability and Honesty and trustworthiness (an additional 26 items). SDQI and SDQII were used in this study. SDQI and SDQII have satisfactory internal consistency and validity. The lowest possible score for the total SDQI is 76, whereas, the highest possible score is 380. The lowest possible score for the total SDQII is 102, whereas, the highest possible score is 510. Higher scores indicate higher level of self-esteem. There are currently no published cut-off scores to categorize self-esteem as high or low. This instrument is available online free of charge. The researcher translated this instrument to Arabic. In this study Cronbach alpha for SDQI was 0.96 and Cronbach alpha for SDQII was 0.98.

The PedsQL Family Impact Scale (Varni et al 2004b) and the PedsQL Healthcare Satisfaction Hematology/Oncology Module (Varni et al 2000) were also recorded, but these relate to impacts on parents and the wider family and so are reported separately.

Translation

Arabic versions of these instruments were used in data collection. In order to retain the integrity of the original instrument (in English), a well-established process of back-translation was employed (Brislin 1986). The rigour of this approach is commended by Jones (2003). More detail of the process is provided by Al-Gamal & Long (2012). Once back-translation had been completed, two experts in family mental health were asked to check the appropriateness of the questionnaires to measure what was intended to be measured (face validity). They considered the whole scale and each item, reviewing relevance, appropriateness and completeness in scope, and finding lack of ambiguity and a good fit with the intended population. In order to identify potential problems with feasibility or processes, a pre-test of the questionnaires was completed with 10 children. Minor amendments were made to processes and then data collection could proceed.

Ethical approval and ethical considerations

Formal research ethics approval was secured from the University of Jordan and from the healthcare institution. Long (2007) suggests that the researcher should identify the risks to participants and plan relevant measures to avoid, minimize, or treat the harms that may ensue. In this study, the main risk was that answering the raft of questionnaires might trigger emotional distress in children. However, the researcher was trained to deal with emotionally affected participants (by virtue of qualifications and a specific training course completed before the study). Had a child required further psychological or emotional support, the clinical psychosocial team at the hospital was ready to provide this. No such distress occurred. Voluntary participation was emphasized to study participants. To maintain privacy, participants' names and personal details were not recorded in participants' responses, and each child had a study identification number.

Statistical Methods

IBM SPSS version 21 was used in data analysis (IBM Corp, Armonk, NY, USA). Descriptive statistical analysis (frequency count, percentage, mean, median and standard deviation) were employed to describe participant characteristics. T-test was carried out to examine the effect of

gender on scores for the main attributes. Bivariate correlation analysis was applied using the Pearson product-moment correlation coefficient to assess the association between the selected variables (including child HRQL, fatigue, psychological functioning, and self-esteem). Ninety-five percent (95%) CI for the correlation coefficient for the primary comparisons was used. Statistical significance was set at $p \leq 0.05$. The underlying assumptions of normality for the use of t-test were verified through descriptive tables, normal P-P plots and the Kolmogorov-Smirnov test (Garson 2012).

RESULTS

Demographic characteristics

The age range of the children was 5-16 years (mean 10.17, SD 3.4 years). Thirty were girls and 40 were boys. The majority of the children ($n=34$, 46%) had leukemia, 4 (5.7%) had lymphoma, and 32 (48.3%) other types of cancer.

Quality of Life

The PedsQL 4.0 Generic Core Scale total scores ranged from 21 to 100 (mean 65.5; SD 17.6). Table 1 details the means scores and standard deviation for total quality of life and subscales. Subscales mean scores ranged from 48.25 for the school functioning subscale to 78.14 for the social functioning subscale.

[Insert table 1 here]

Fatigue

For the PedsQL Multidimensional Fatigue Scale, the total scores ranged from 12.5 to 100 ($m=65.79$; $SD=22.20$). The mean score for the subscales ranged from 60.86 for the sleep/rest fatigue subscale to 70.90 for cognitive fatigue subscale. See Table 2.

[Insert Table 2 here]

Self-esteem

Means and standard deviations were calculated for the SDQI/SDQII and its subscales for the children. The results showed that *General self* was the highest ranked of the subscale scores, followed by *Parents' relationships*, then *General school*. The lowest mean score was for the *Physical ability* subscale. The results are presented in Table 3.

[Insert table 3 here]

Relationship between self-esteem, fatigue and quality of life

The results of the relationship between fatigue and quality of life as demonstrated by these two scales are shown in Table 4. There were significant positive correlations between the PedsQL Multidimensional Fatigue Scale and all of its subscales and the PedsQL 4.0 Generic Core Scale and all of its subscales. This indicated that higher fatigue total scale and subscale scores (fewer problems or symptoms) were correlated with higher overall quality of life scores (better overall HRQOL). Children with high levels of fatigue experienced poorer quality of life.

[Insert table 4 here]

The results indicated that there were significant weak positive correlations only between the SDQI/SDQII *physical ability* subscale and both the total PedsQL 4.0 Generic Core Scale total

score and its *physical functioning* subscale. This means that children with high quality of life and high physical functioning were also likely to exhibit higher physical ability self-esteem ($r=0.355$, $p=0.003$; $r=0.272$, $p=0.023$ respectively).

Relationship between demographic characteristics and related variables

Correlational analysis was applied to explore the association between child characteristics and the PedsQL 4.0 Generic Core Scale total score and subscales. There was no statistically significant correlation between age of the child or family income and total scale score or any subscale scores. The effect of gender on total score and on all subscale scores was calculated using two-tailed t-test. There was a statistically significant difference in this study in PedsQL 4.0 Generic Core Scale total score and the *physical functioning* subscale between boys and girls ($t(68)=2.59$, $p=0.01$), $t(68)=2.99$, $p=0.004$) respectively. The results indicated that boys experienced better total quality of life and better physical functioning than girls. Correlational analysis was performed to examine the association between child characteristics and PedsQL Multidimensional Fatigue Scale scores. There was only a weak negative statistically significant correlation between age of the child and PedsQL Multidimensional Fatigue scale score ($r=0.242$, $p\leq 0.05$) and the general fatigue subscale ($r=-0.293$, $p\leq 0.05$).

Moreover, there was no significant correlation between age of the child and total SDQI/SDQII score. However, age of the child correlated positively and statistically significantly with the *general school* subscale score ($r=0.245$, $p=0.03$), indicating that older children experienced higher perception in this domain than younger children. This may be expected as teenage brings in preparation for formal examination and more self-directed learning and motivation. A two-tailed t-test revealed a statistically significant difference in total S-DQ score between boys and girls ($t(68)=-1.867$, $p=0.04$), suggesting that girls had lower self-esteem than boys. Moreover, the results indicated that there were statistical differences in *parents' relationships*, *readings* and *general self*-subscales between boys and girls ($t(68)=-2.133$, $p=0.02$, $t(68)=-2.155$, $p=0.02$, $t(68)=-2.230$, $p=0.08$ respectively). Girls perceived lower *parents' relationships*, *reading abilities* and *general self* than did boys.

DISCUSSION

The key factors that determined HRQL, fatigue and self-esteem in children and young people with cancer in this study revolved mostly around physical ability and physical functioning in both quality of life and self-esteem. The complex relationship between such factors can hardly be underplayed, particularly in older children, and additional qualitative data is probably required to tease out the interplay between physical and emotional aspects of a child's life. However, as children grow older and more physically active in play and leisure, then reduced physical ability could easily lead to limitations in joining in, physically going where friends go and doing the things that they do. Indeed, major problems were found with fatigue, linked to physical ability, and pervasive across various aspects of fatigue. This might be expected to lead to dislocation of friendships and poorer perceptions of relationships with peers. This poses a challenge to nurses working in the community and in specialist outreach roles to predict such difficulties and to plan strategies with young people and their families to minimize the effects of such deficiencies.

To a lesser degree, school functioning, with constituent elements of mathematics and reading, was problematic for quality of life. This was more of a problem for girls than for boys, but with no particular age group involved, however fatigue associated with school was clearly a problem more for younger children than older ones. Moreover, girls' self-esteem was more badly affected overall and for reading specifically than self-esteem in boys, though self-esteem was less of a problem as children became older. Further research is needed to understand these issues, particularly in Arabic countries in which there is segregation by sex at school. There is recent evidence from meta-analysis in Denmark that interventions to improve return to school can be effective in reducing anxiety and depression in the student with cancer, and improved knowledge and understanding in classmates promotes reduction in fear and increased support for their colleague as well as promoting a positive attitude towards the child with cancer (Helms et al 2016). In countries that provide a school nursing service there is clearly an opportunity to implement such intervention based on understanding of the complexity of HRQL, self-esteem and fatigue.

While individual sub-scale scores could often be inconclusive or borderline normal, total scores could show serious impairment. It is possible that the size and nature of the sample may have led to this phenomenon, and caution is indicated in over-analysing in such circumstances. An integrative review from Brazil by Nunes et al (2014) recognised the common difficulty in assembling sufficiently large samples for single-diagnosis studies of fatigue experienced by children and adolescents with cancer, and acknowledged that including several diagnostic categories of cancer may be necessary in order to undertake worthwhile studies.

Fatigue while on-treatment is commonly reported and may be due to interrupted sleep, particularly from frequent nursing or medical attention, noise, and the effects of medication (dexamethasone, for example). Studies from the USA and The Netherlands have shown that nursing action to reduce these disturbances through pharmacological and non-pharmacological strategies can ameliorate the impact on HRQL. These can include practical management of the ward environment (Linder & Christian 2012) as well as psychological measures (van Litsenburg et al 2011).

This study has uncovered something of the problems faced by children with cancer in Jordan, emphasising the need to assess the need and optimize the psychosocial and educational support for children and their families throughout the experience of cancer from diagnosis to long-term follow-up. The findings from this study could help nurses and other health professionals to recognise the complex connections between self-esteem and other study variables and to inform their actions in intervening to mitigate predictable negative outcomes for children with cancer.

CONCLUSION

This is the first study to investigate the relationship between these variables in a Jordanian population. The results of the study shed light on the quality of life and self-esteem of a group of children during their treatment for cancer and the difficulties they face to re-engage with the community and with school. The outcomes may prompt the development of guidelines for

routine assessment of these factors when children have been diagnosed with cancer, leading to better nursing responses to the challenges that families need to overcome in the years following the diagnosis.

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Table 1. Means and SD for PedsQL 4.0 Generic Core Scale total score and subscales scores

Domain	Mean (SD)
Physical functioning	63.95 (23.72)
Emotional functioning	75.08 (25.39)
Social functioning	78.14 (23.92)
School Functioning	48.25 (23.18)
Psychosocial Health Summary	67.31 (18.0)
Total Summary Scores	65.57 (17.65)

Table 2. Mean and SD for PedsQL Multidimensional Fatigue Scale and subscales

Domain	Mean (SD)
General Fatigue	65.79 (33.1)
Sleep/rest Fatigue	60.86 (24.6)
Cognitive Fatigue	70.90 (26.15)
Total Fatigue	65.79 (33.1)

Table 3. Means scores and SD for total S-DQ score and subscales

Domains	Mean	SD
Physical appearance	36.6	9.7
Physical ability	30.7	11.5
Parents relationships	38.5	9.9
Peer Relations	34.3	11.3
General-school	38.1	16.6
Reading	34.2	15.5
Mathematics	33.6	16.6
General-self	41.3	11.8
Total S-DQ	36.0	10.5

Table 4. Pearson Correlation Coefficients between PedsQL 4.0 Generic Core Scale and PedsQL Multidimensional Fatigue Scale

PedsQL	Total Fatigue	General Fatigue	Sleep/rest Fatigue	Cognitive Fatigue
Total score	.690**	.654**	.524**	.441**
Physical functioning	.563**	.487**	.493**	.353**
Emotional functioning	.444**	.524**	.246**	.242*
Social functioning	.364**	.332**	.272*	.255*
School Functioning	.596**	.497**	.516**	.398**
Psychosocial Health Summary	.615**	.602**	.453**	.384**

** . Correlation is significant at the 0.01 level (2-tailed).

* . Correlation is significant at the 0.05 level (2-tailed).